

Advocacy: To What Should We Aspire?

Address of Commission Chairman Clarence J. Sundram at the Annual Conference of the Young Adult Institute, New York City, April 13, 1989

Last year, I came here with a "work in progress" to share with you my thoughts about why regulators have gone mad. Today, I will present another "work in progress" — an elegant term for some half-baked ideas that haven't been fully thought through. The title of my talk is rather presumptuous — "Advocacy: To What Should We Aspire?"

The reflections I want to share with you are the product of 15 years as an observer of human service systems and programs; of government at work in developing policy; as a participant in legislative and executive debates, discussions and negotiations; as a monitor and investigator for the executive and judicial branches of government of programs for people who are disabled; and as an advocate who is paid by the government. **Litigation as a "Clumsy Tool"** As a lawyer who has been involved in the field of mental disabilities, I have done my share of reading, thinking and arguing about the concepts of "rights" as they apply to people with mental disabilities. In the type of litigious society in which we live, court calendars are filled with cases arguing about a patient's right to due process in the commitment procedure; about a right to protection from harm in an institutional setting; about a right to treatment in the least restrictive environment; about a right to refuse treatment; about a right to a free and appropriate education; about a right to liberty, and so on.

Underlying all this litigation is an enormous sense of frustration at the inability of large and expensive governmental systems to see each person as a unique individual, with his or her own human needs. As the historian, David Rothman, has so compellingly observed, despite the calls of conscience that have filled the law books with requirements for individualization — witness the IEPs and IHPs and the like — the demands of convenience often reduce services to the lowest common denominator in actual delivery.

Creative lawyers have thus devised elaborate procedural concepts, laden with legal jargon and ritual, to achieve a rather simple objective — to force greater professional attention on the unique needs of each individual. Stripped of their embellishments, these legal arguments about rights with fancy names are nothing more than pleas for a recognition of human dignity — where humanity and ability are recognized first and disability placed in perspective; where the value of freedom, choice and a normal life are not sacrificed too casually, where respect for an individual's needs and wants shapes the governmental response. It seems to me that, if what is at the root of our disenchantment with service systems is an absence of an appropriate sense of values about, and a respect for, basic human dignity, or a systemic inability to actualize such values, then litigation is a clumsy tool. The legal process may be able to force people to act as if they care, but it cannot actually get them to care, and that makes all the difference.

Getting a human service system to comply with unavoidable and unambiguous legal duties

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often turns out to be too unsatisfying as an objective — a skeleton without the humanizing vitality of emotions, without flesh or blood. The struggle to create unambiguous legal duties often results in the types of regulatory minutiae I have spoken of earlier, which surrender the civilizing expectation of true human caring in exchange for a stark set of compliance measures. And when legal victories seem to be won, they often turn out to be hollow ones, followed by endless debates about the scope and extent of the changes that may be legally necessary.

Changing Practices/Expectations

As I see it, whether out of strategic necessity or the absence of better alternatives, advocates, like clinical professionals, have often been guilty of measuring out the lives of their clients in coffee spoons, as T.S. Eliot would describe it. While clinical professionals devote enormous resources to elaborate measurements of minute gains in learning, advocates often content themselves with equally small improvements for large efforts — e.g., moving clients from an open ward to one which is partitioned for more privacy; replacing old institutional buildings with newer ones; moving from a large institution to a smaller "community" ICF of 50 or 30 or 12 beds.

I don't mean to dismiss the value of these improvements in the human condition of people we are trying to help. We must feed the hungry while we search for ways to eradicate the famine. But, to content ourselves with such "progress" is to accept the legitimacy of public policies that continue to segregate and isolate people on the basis of their disability.

Evolving Civil Rights Laws

Just as the written civil rights laws are evolving to include disability along with race, sex, ethnic origin, as prohibited bases for governmental discrimination, so too should our practices and expectations change. It should be no more legitimate to create institutions — whether in remote areas or in neighborhoods — for people who are disabled than it is to create housing projects for racial minorities. The evil of segregation is the same.

The discomfort that many of us feel with our "accomplishments" in promoting community-based small ICFs is reflected in the increasing concerns over "quality of life" and "integration." It is not uncommon to hear debates about whether a recreation program that entails piling all 12 residents of a group home into a van to go to the movies and sit together in a group is really integration or a more subtle form of segregation.

I am afraid that we are going to be spending a great deal of time and efforts in debates like these until we come to grips with the only policy goal that is morally and ethically defensible and one to which I suggest we aspire — equality in the treatment of people with disabilities. The test is simple: whatever we would not want for ourselves, we should not prescribe or adopt as public policy for people who are disabled.

So, if we would not want to live in institutions, we ought not to adopt or countenance a public policy which requires it for a disabled person.

If we would not choose to spend our lives with 12, 10 or 6 other adults, we ought not to adopt or countenance a public policy that forces this "choice" on a disabled person.

Moving Towards Equality

If it is essential to the quality of our lives that we have the opportunity to form relationships with others, freely and by choice, we ought to promote similar opportunities for people who are disabled.

This may sound like the dreaming of a naive idealist whose mind isn't weighted down by reality. It may sound too difficult and perhaps impossible to achieve truly equal treatment of people who are often severely disabled. Certainly our history would support this view that the task is difficult, perhaps too difficult.

Lionel Trilling was right when he observed the inevitable progression by which the objects of our pity become the subjects of our concern and "finally the victims of our coercion." He might have added that the process usually starts with labeling the objects, which helps strip them of some of their humanity to distance "them" from "us."

This process has been at work in our history of providing for people with severe disabilities.

We have invested millions and billions of dollars in edifice complexes and, when they are proven irrefutably not to work, to brutalize rather than enrich the lives of the people they are intended to help, our minds are so captured by this way of thinking that we can only think of alternative forms of institutions in which to contain them. We think of 12-bed community institutions as progress — and perhaps they are. But they proceed from the same faulty premise that a disability needs an institution in which to confine it. We have created a powerful juggernaut of professionals, unions, staff and, sometimes, even families, which have become dependent on this way of life, fueled and bonded together by public policy decisions and funding streams which flow for institutional placements but which are dammed for normal living. As advocates, we have often reduced ourselves to quibbling about irrelevancies at the

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margins — are 6 beds better than 10? Does it make a difference whether the 12-bed facility is on the fringe of a 1000-acre campus or located in the middle of nowhere in the "community?" What new forms of measurement and analysis can we find to reduce human life to inputs and outputs, aided by our new-found infatuation with computers?

It seems to me that advocacy has to proceed from a bedrock belief in a notion of equality. We share a common humanity with people we label. Like us, they have abilities and competencies. Like us they have needs and incompetencies. How we approach the challenge of dealing with their needs ought not to differ from how we approach our own needs to compensate for our own incompetencies. Perhaps it would help if more of "us" viewed ourselves as "temporarily" non-disabled. After all, we are all just one accident away from becoming one of "them."

Basis for Hope

I think recent history provides a basis for hope. About 15 years ago, as an Assistant Counsel to then Governor Hugh Carey, I toured Willowbrook and heard from professionals why the residents of that institution really needed to be there because they weren't capable of survival anywhere else. (It later occurred to me that if they could survive there, they could survive anywhere!)

A few years and several hundred community placements later, I heard, "Yes, a few of the higher functioning people might be exceptions, but most of these people are too retarded to benefit from living in a community residence."

And, later, I heard, "Well, it's true that many retarded people might benefit from living in the community, but there will always be a need for institutions."

It is really something to marvel at and to take pride in, that in a few short years, as a result of the efforts of so many of you, those statements today seem ludicrous. Yet, it seems like yesterday that they represented a respectable body of professional opinion. But, today, it is a satisfying reality to note that for every example of a severely disabled, multiply-handicapped, non-verbal, medically frail, non-ambulatory (and you can add the adjectives and labels)—forevery such example of a person who "needs" an institution or a specially-staffed ICF, one can find, somewhere in America, perhaps in the same state, county or city, a similarly disabled person who isn't segregated and institutionalized. With the help of family or caring friends, imaginative professionals and flexible government officials, such a person might be having his needs met in a normal home, with a natural or surrogate family, living with more freedom and dignity, with more opportunities to form and maintain real human relationships, to enrich his own life and those of others around him. Such experiences exist all over the country. Severely disabled people are remaining in and returning to communities, are learning and exercising choices of which they were once thought incapable. The normalcy of their lives, and the ability of caring individuals, professionals and governmental support programs to sustain and nurture them, is living testimony to the lie that a severe disability needs an institution within which to be confined

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and segregated. They are living proof that implementing a doctrine of equality is not nearly as far-fetched as it may sound.

What needs institutional confinement, segregation and isolation is our own lack of imagination, courage and audacity to push public policy towards making *this* experience the norm, and segregated facilities, institutional or community, large or small, relics. People with severe disabilities need the same chance at a normal life, with its risks and rewards.

The notion of equality to which I suggest we aspire is *not* merely the equal treatment of two similarly disabled groups of people so that all disabled people might have the same opportunities, although that would be enough of a start to keep us all occupied for at least the next decade. No, that is too modest a goal. **Reference Point for Equal Treatment**

I suggest that the reference point for equal treatment is the non-disabled citizen, with whom the disabled person shares common legal rights and protections under the law. The notion of equality ought to recognize the intrinsic equal worth of a human life, and not merely its capacity to produce goods or services. Those of us who have personal relationships with people who have severe disabilities recognize that we share a common ability to learn and to teach, to experience emotions, to enjoy friendship, to give and to receive.

The Constitution protects us equally — disabled and non-disabled alike. The state and federal laws increasingly recognize that disability is no basis for discrimination and segregation. And the Supreme Court in *Cleburne* has made it clear that classifying people with disabilities for different treatment than the community-at-large will not withstand scrutiny if it is arbitrary and irrational, and based on ignorance or prejudice. Separate but

equal is still an unacceptable doctrine. There is a skeletal legal framework in place to promote a policy of equal treatment of people with disabilities. But it needs to be given life and vitality through the advocacy efforts of more than lawyers alone. All of you—those who have disabilities, as well as families and friends, co-workers, governmental officials, service providers and staff, and advocates — need to raise your voices and your expectations. There is a massive task that lies ahead to learn from our success in community integration, to educate policy-makers, professionals and the public about the need to change practices that have out-lived their defensibility, to erode the general acceptance of segregation of people with disabilities as neither arbitrary nor irrational. In short, we must do better to articulate "the evolving standards of decency that mark the progress of a maturing society."

Implementing such a policy of equal treatment will be a challenge, as it will require a fundamental reassessment of the manner in which service delivery systems have been structured.

We may, for example, no longer be able to develop facilities just for people with disabilities. Not only would such institutions be inconsistent with such a notion of equality, but so would many group homes. Instead, we would be forced to think about what needs people with disabilities have in common with others not similarly labeled — whether for medical care, nursing assistance, physical therapy, habilitation training and the like. We may find ourselves accelerating the development of policies and funding programs that enable people to design their own community living arrangements, family supports, and personal care, with assistance if they need it.

Changes such as these may prompt us to think long and hard about our beliefs in equality and equal treatment but, if we are to aspire, let's not aspire to something too easy.

It is appropriate, on a day when a Burton Blatt Award is being made, to close with a quotation from *The Conquest of Mental Retardation*: "My main purpose is to arouse if not disturb you, to force you to examine not only the dilemmas in their lives (people with disabilities), but also those in your life, to help you understand better that if aspects of our work seem unresolvable, it is because they are — if only for the moment — unresolvable."

YAI Workshops

The Young Adult Institute has announced a series of workshops of interest to facilitators who work with the families of infants and young children with developmental disabilities, as well as young adolescents and adults with developmental disabilities. The workshops are:

- ? "Working Effectively with Families of Infants and Young Children with Developmental Disabilities: Parent Training Workshop," September 25-26 and November 15-16, 1989;
- ? "Workshop on Creating Parent/Professional Partnership in the Transition and Employment of Young Adolescents and Adults with Developmental Disabilities," October 19-20, 1989;
- ? "Working Effectively with Families of Infants and Young Children with Developmental Disabilities: Advocacy Skills Training Workshop," November 2-3 and December 6-7, 1989.

The workshops will be held at the Young Adult Institute, 460 West 34th Street, New York City. Cost for each two-day workshop is \$195 for professionals and \$145 for parents and students. For further information contact YAI at (212) 563-7474.